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Patient-reported outcome measures (PROMs) in healthcare chaplaincy: What, why and how?¹



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ABSTRACT

Outcome research is becoming increasingly important in healthcare chaplaincy, to improve the quality of chaplaincy care and to justify the need for healthcare chaplaincy services. Patient-reported outcome measures (PROMs) are instruments enabling the assessment of healthcare chaplaincy outcomes. In this paper, I discuss how PROMs might be implemented in healthcare chaplaincy. PROMs can be used for patient monitoring, quality improvement and external transparency. PROMs can reflect any dimension of patient health and functioning, but they must be sensitive to change and relevant to the chaplaincy care context that is being evaluated. The choice of PROs assessed reflects the vision on the profession and its responsibility. Reduction of the profession to that which can be measured with PROMs should be avoided. Thus, the selection and implementation of PROMs in healthcare chaplaincy requires careful considerations, which can be supported by use of the PROM cycle illustrated in this paper.

Keywords

Healthcare chaplaincy, outcome, assessment, spiritual care, questionnaire

List of terms

- PREM:** Patient Reported Experience Measure, a self-report instrument used to assess the evaluation of a care encounter
- PRO:** Patient Reported Outcome, an aspect of health, well-being or functioning that is affected by a care professional, intervention or organisation
- PROM:** Patient Reported Outcome Measure, a self-report instrument used to assess PROs
- ROM:** Routine Outcome Monitoring, a practice in which patients complete PROMs or PREMs at regular intervals before, during and after care

Introduction

With the secularisation of many societies, healthcare chaplaincy is increasingly defined, organised and evaluated as a healthcare profession rather than a religious profession². With this development, outcome research has become one of the top priorities in research on healthcare chaplaincy in various European countries and the United States of America (Damen, Delaney & Fitchett, 2018; Damen, Schuhmann, Lensvelt-Mulders & Leget, 2019; Selman, Young, Vermandere, Stirling & Leget, 2014). Outcome research means that we try to understand what has been changed in a patient after seeing the chaplain. We might want to know this for several reasons, such as (a) to monitor progress of the patient in relation to their spiritual need, (b) to understand the general effectiveness of chaplaincy care at alleviating spiritual needs, (c) to compare the effectiveness of several different types of chaplaincy care in relation to a certain spiritual need and (d) between various groups of patients, (e) to explain to healthcare professionals with whom healthcare chaplains collaborate what it is that they do, (f) to compare the effectiveness of chaplaincy care at alleviating certain needs to that of other healthcare disciplines, or (g) to report on how healthcare chaplains contribute to the goals of a healthcare institution or other funding body, such as an insurance company or governmental organisation. Therefore, outcome research could provide evidence for the impact of the healthcare chaplain on the patient for use in patient care and in communication with patients, chaplains, (mental) healthcare providers, and funding bodies.

Such research can be conducted with various methods. One approach could be to use a diverse array of qualitative methods to describe the thoughts, feelings and acts of chaplaincy patients before, during and after one or several meetings with the healthcare chaplain. An important advantage of this approach is that the described outcomes are close to the actual experience of the patient and the descriptions can consider various possible contributors to this outcome. An important disadvantage is that the described outcomes can be unique to this per-

son under these circumstances and are, thus, difficult to compare between patients, chaplains, interventions, settings, etc. In other words, the outcomes are not standardised, which makes comparative research and generalisation of findings more difficult.

A quantitative approach to outcome research will more easily allow for standardisation and, with that, the generalisability and comparability of findings. One method for such a quantitative approach is the use of Patient-Reported Outcome Measures or PROMs. In this paper, I will introduce what PROMs are, why they can be useful for outcome research in healthcare chaplaincy, and how they can be constructed and implemented. Throughout, I will provide examples of existing chaplaincy research using PROMs.

Outcome research in healthcare chaplaincy is not without controversy or challenges. Various authors have suggested that it is important for healthcare chaplains to conduct scientific research on the impact of their practices, to understand whether chaplains support patients in the ways they hope for and, with that, to enable quality improvement of chaplaincy care. Additionally, current emphasis on evidence-based practice in healthcare throughout the world, but especially in Western countries, has led to a situation in which there will be no or little funding for care if there is no evidence to support its effectiveness (Fitchett, 2011; Handzo, Cobb, Holmes, Kelly & Sinclair, 2014; Snowden et al., 2017).

However, others have argued that an emphasis on so-called Outcome Oriented Chaplaincy (VandeCreek, 2014) might devalue healthcare chaplaincy, which is strongly oriented toward a practice of presence (Nolan, 2013, 2015). Because of the value placed on presence, relationship and person-centred care, much of healthcare chaplaincy might not lend itself to the demarcation, predictability and replicability required for scientific research. In addition, there is a risk that, in the quest for evidence-based practice, healthcare chaplaincy might be reduced to the aspects of the discipline that can be assessed through scientific methods.

Damen, Schumann, Leget, and Fitchett (2019) provide counterarguments for many of the ob-

jections against outcome research in healthcare chaplaincy. Here, I would like to stress that I believe that the careful use of outcome research, that keeps in mind that not everything of value can be measured, has the potential to not only stimulate more deliberately reflexive chaplaincy practice (Asking why do we do what we do?), but also to make it more clear to chaplains themselves and to the people they interact with what chaplaincy care is about (Asking what is it that we do?).

Nevertheless, outcome research in healthcare chaplaincy is not easy, because it is diverse, sometimes unarticulated, and often unpredictable. In addition, healthcare chaplaincy affects not only spiritual, but also physical, psychological, and social aspects of patients' health and functioning (Damen, Schuhmann, Leget, et al., 2019), thereby showing overlap with outcomes of other professions. Furthermore, other care professions also affect spiritual needs (Sinclair, Pereira & Raffin, 2006), which makes it difficult to determine whether it was the healthcare chaplain or somebody else who stimulated the change in the patient's health or functioning.

Thus, careful consideration of which outcomes are to be assessed, and how and when this happens is important: What is the nature of healthcare chaplaincy in the specific context and what is the responsibility of the healthcare chaplain? If PROMs are used for this assessment, this paper can assist to embark on it with care and deliberation.

What are PROMs?

The origin of PROMs lies in evidence-based medicine. In evidence-based medicine, the individual clinical expertise of the practitioner is integrated with external evidence from systematic clinical research on, among others, the efficacy and safety of interventions to enhance the quality of decision making about treatments for specific patients (Sackett et al., 1996). Preferably, efficacy was assessed with objective measures, such as how far a patient can walk or how much damaged tissue is still present. However, it is increasingly recognised that health is a subjective experience and that emotional and evaluative factors are at least as important as objective indi-

cators to understand the success or failure of a certain treatment. Therefore, measures that assess the patient's experience of their health are needed (Terwee, Wees & Beurskens, 2015). PROMs are such measures.

PROMs typically are self-report questionnaires on which a patient can score the extent to which a certain aspect of health or functioning (also often referred to as "quality of life") is present. These aspects are called patient-reported outcomes (PROs). If the patient is not capable of reporting on these themselves, oftentimes a representative of the patient is asked to report on behalf of the patient. PROs can cover any dimension of health or functioning, such as physical capabilities (such as being able to climb a flight of stairs without getting out of breath) or sensations (such a pain, fatigue or numbness), emotions (such as insecurity, anxiety or depression), thoughts (such as suicidal ideation or cognitive capabilities), evaluations (such as feelings of safety or overall quality of life), social experiences (such as feeling supported by loved ones or looking forward to going to social events) or spiritual experiences (such as experiences of meaning in life, connectedness to the transcendent or awe). In any case, a PRO is an aspect of the patient's health or functioning that is being addressed by the intervention or profession under scrutiny. Thus, an important characteristic of PROs is that they are amenable to change and that they are relevant for the context in which the PROM is being used (Terwee et al., 2015). For healthcare chaplaincy, this means that PROMs should only assess aspects of the patient that change due to the chaplaincy encounter.

Usually Likert-type scales are used for this self-report, in which the patient must tick a box or circle a number after each PRO on the questionnaire. The lowest score means the PRO is "absent" or "not applicable" and the highest score means it is "very severe" or "highly applicable". Jensen Hjermstad et al. (2011) suggest that no less than three and no more than seven answer categories should be offered, because otherwise the discriminatory ability of the measure is lowered. Sometimes visual analogue scales (VAS) are used. A VAS is a straight hori-

zontal or vertical line of about 10cm, either with or without indicated scores as in a Likert-type scale. The patient then must draw an intersecting line to represent the level to which they experience the given symptom (often pain).

An example of a PROM for healthcare chaplaincy is the recently developed “Scottish PROM” (Snowden & Telfer, 2017), which is currently being translated to other contexts as well by the European Research Institute for Chaplains in Healthcare (ERICH). In this self-report questionnaire, the patient is asked to tick the box that best describes their experience in the past two weeks. The scale consists of a 5-point Likert-type scale with the categories “None of the time”, “Rarely”, “Some of the time”, “Often”, and “All of the time”. The five outcomes that are being assessed are: being honest with oneself about how they were really feeling, having a positive outlook on their situation, feeling in control of their life, feeling a sense of peace, feeling anxious. The Scottish PROM is a so-called generic measure, in contrast to a disease-specific measure, which assesses aspects of health and functioning specific to a certain (mental) health condition. This means that the Scottish PROM can be applied to a wide variety of patients. The outcomes that are measured by this PROM pertain to mental health, as evidenced by its strong relationship with the Warwick-Edinburgh Mental Wellbeing Scale ($r = .80$). This means that it is unlikely that these outcomes are specific to chaplaincy care. Other care professions, such as nurses, social workers or psychologists, might also attain them.

PROM or PREM?

The Scottish PROM is a particularly interesting example, because it also contains a PREM: A Patient-Reported Experience Measure. PREMs assess how the patient evaluates the care encounter (Bos, Zuidgeest, Kessel & Boer, 2015). This can be any aspect of the visit, from the ease of making an appointment or the ease of finding a parking space to the attitude of the healthcare chaplain. The PREM in the Scottish PROM consists of four items, that assess whether the patient felt listened to by the chaplain, was able to talk about what was on their minds, felt their

situation was understood, and felt their faith or beliefs were valued. The rating scale is the same as for the PROM section of the questionnaire.

This distinction between PROMs and PREMs is important to note, because much research in chaplaincy currently uses patient satisfaction as an outcome. For example, Sharma et al. (2016) examined the difference in patient satisfaction between interventions addressing the spiritual/religious dimension of patients and interventions addressing the psychosocial dimension. Other studies have examined whether patients who had seen a chaplain during their hospital stay were more satisfied with care than patients who had not seen a chaplain (For an overview see Fitchett, 2017; Pesut, Sinclair, Fitchett, Greig & Koss, 2016). However, patient satisfaction is a PRE, not a PRO. Patient satisfaction does not reflect health or functioning, but the evaluation of the care process. Of course, it is important that patients are satisfied with their care and it is great that chaplains contribute to this. However, the general goal of chaplaincy is to alleviate spiritual needs. Thus, the extent to which certain spiritual needs were reduced would be a PRO of healthcare chaplaincy.

Unfortunately, even when research is focused on spiritual needs, it is not immediately clear whether the measure used is a PREM or a PROM. This is illustrated in the study by Flannelly, Oettinger, Galek, Braun-Storck, and Kregger (2007). They have investigated whether various aspects of the healthcare chaplain’s demeanour (such as, whether the chaplain introduced themselves to the patient, provided privacy, or seemed to care) and various aspects of patient satisfaction were related with how well the patient felt the chaplain had met their spiritual and emotional needs. In this study, whether the “outcome” is a PRO or a PRE depends on how the patient interprets the question asked: “How well did the chaplain meet your spiritual needs?” If this is interpreted as whether the needs were reduced, this is a PRO; but if it is interpreted as whether the needs were addressed, this is a PRE. The patient satisfaction items used in the study were derived from Vandecreek (2004) and included, among others, the items “How satisfied were you with the chap-

lain's ability to really listen to you?" or "(...) provide a referral for other help you needed?" – clearly PREs –, but also "(...) overcome your fears or concerns" or "(...) help you tap your inner strength and resources?" – which are PROs. The VandeCreek items were more closely related to the extent that patients felt their needs were met (with r ranging from .22 to .54) than the items on the demeanour of the chaplain (with r ranging from -.03 to .38), with the two PROs showing the strongest associations ($r = .53$ and $r = .54$, respectively). Thus, it seems that most patients had interpreted the question "How well did the chaplain meet your spiritual needs?" as whether their needs had been reduced by the chaplain (as a PRO).

Why are PROMs used?

In the introductory section to this paper, I already mentioned several reasons for conducting outcome research. These can be categorised into three overarching motives: (a) individual patient care, (b) quality improvement, (c) external transparency (Verkerk et al., 2017).

Individual patient care

In individual patient care, PROMs can be used for diagnostic purposes and/or to provide the patient with more insight into their level of health or functioning. They can also be used to monitor the patient's needs throughout care. In this instance, the assessment can be used to facilitate communication between the healthcare chaplain and the patient and/or for care decision making.

Within mental healthcare, continuous use of PROMs in patient care is referred to as routine outcome monitoring or ROM. ROM makes use of computer systems in which the patient provides weekly reports on a PROM (and sometimes also a PREM) for the duration of treatment. The therapist and the patient receive feedback on the patient's progress in the form of charts or other visual representations (such as traffic lights or smileys) to evaluate whether a patient has recovered, improved, remained unchanged, or deteriorated. This can then be discussed in the next meeting and used for treatment decision making. Lambert and Harmon (2018) suggest

based on effectiveness studies of ROM, that the use of ROM has a positive impact on treatment effectiveness, because it raises the therapist's and patient's awareness of the therapeutic process; it can help to make therapists expectations about the successfulness of their treatments more realistic; it can help to predict – and thereby prevent – treatment failure; and – when including a PREM – it can help to strengthen or maintain the therapeutic alliance. Especially when used for monitoring, it is useful to record the scores of the patient on the PROM in their clinical records.

Quality improvement

When using PROMs for quality improvement, the scores of individual patients are not important. Instead, the assessments from a group of patients of a specific healthcare chaplain, department or organisation are used to determine whether on average the care is showing the desired effects or, in other words, whether the desired outcomes of care are being obtained. If not, it needs to be determined why the care outcomes are insufficient and what arrangements need to be taken to improve the quality of care. Using PROMs for quality improvement often involves some type of "benchmarking": The results obtained for one professional, department or organisation are compared to a professional, department or organisation that is considered very successful (a "best practice"; Camp, 1989). When used for this purpose, the scores on the PROMs are not made public to patients or external organisations. The information is for internal organisational use only.

Research into the effectiveness of healthcare chaplaincy also falls under the quality improvement motive for using PROMs, though the findings from this research are generalised and used beyond the organisations in which the data were obtained. The general assessment of the effectiveness of chaplaincy care and comparisons between chaplaincy interventions, between types of chaplains, between types of healthcare professionals, and between patient groups all facilitate an understanding of the extent to which chaplaincy alleviates certain (spiritual) needs and what might be needed to improve

this. This knowledge can help decision-making in the individual patient encounter – in the spirit of evidence-based practice – because it can contribute to an understanding of which approach might be most helpful to whom, under which circumstances, by which care professional (especially in multi- or transdisciplinary care) or by which type of healthcare chaplain. In addition, this research can help to communicate about healthcare chaplaincy with other professions. ROM data can also be used for this research, although often the measures used in ROM do not have enough psychometric quality for scientific research. I will discuss quality criteria for PROMs in the next section.

An example of chaplaincy research for quality improvement is the Life in Sight Application (LISA) study by Kruizinga, Scherer-Rath, Schilderman, Sprangers and Van Laarhoven (2013). In this study the effectiveness of the LISA intervention, developed by the authors, is examined. The PROMs used to assess the outcomes of the intervention are the EORTC QLQ-C15 PAL, a disease-specific 15-item self-report questionnaire on quality of life for cancer patients receiving palliative treatment, and the FACIT-sp-12, a generic 12-item self-report questionnaire on spiritual wellbeing (a dimension of quality of life). Both scales are widely accepted and high-quality PROMs that are used by various healthcare professions for quality improvement and scientific research. Therefore, using these scales in healthcare chaplaincy research can facilitate comparison and communication between professions.

Kruizinga and colleagues did not find any differences on these measures between the patients receiving the LISA intervention and patients receiving “care as usual” (Kruizinga et al., 2019). There are various possible explanations for this finding. The authors suggest that the intervention may have been too brief to evoke change, the intervention may have been insufficient in providing resources for finding meaning, or the outcome measures may have been too broad. One of the patient satisfaction items included in the study sheds more light on this latter point. Eighty percent of the participants in the intervention group indicated that they would

recommend the intervention to others, because they felt it had given them insight into their lives and had helped them to see their values more clearly. These outcomes are much closer to the actual elements addressed in the intervention than the outcomes assessed in the two PROMs. I will return to this issue of the specificity of outcomes in the next section.

External transparency

Using PROMs for external transparency means that they are applied at a national level and the results are made public. The idea behind this is that this information will help patients to choose the best possible care. Insurance companies can also use this information for decisions about contracts with healthcare organisations and professionals. The information could also be used by care inspectorates.

However, the use of PROMs for external transparency is problematic for several reasons (NIVEL, IQ Healthcare, VSOP & Patiëntenfederatie Nederland, 2018). First, it is based on a model of competition between care providers, which imposes a risk of reduced cooperation between healthcare chaplains themselves and between chaplains and related professions. Second, combined with the intention of accountability, it imposes the risk that chaplaincy will become focused on care for the assessed outcomes at the expense of valuable outcomes that are not assessed. This would reduce the potential richness of the profession and lead to inattention to various (spiritual) needs of patients. Third, as we will also see in the next section, the interpretation of the scores on PROMs is not easy. Particularly when using PROMs for external transparency, it is important to correct for differences between the populations of healthcare chaplains or organisations. For example, some chaplains may serve a population that, from the start, has more severe spiritual needs than the population of another chaplain. The patients of the first chaplain will likely always score lower on the PROM than the patients of the second chaplain, even though both chaplains provide the same quality of care. Alternatively, the patients of the first chaplain have much more potential for change, than the patients of

the second chaplain do. This also skews the results, when the amount of improvement is taken as the quality criterion. Thus, case-correction is essential for the use of these scores to be meaningful and fair.

Because of these difficulties, PROMs are only used for external transparency when patients are treated for a clearly defined condition, for which it is easy to determine an outcome that they will all have in common, a clear cut-off point (see the next section), and case-correction. PREMs are more commonly used for external transparency, because these are much easier to assess and to standardise across settings (for example, in the form of Consumer Quality Indexes).

How are PROMs constructed and implemented?

So far, I have discussed various purposes for using PROMs in healthcare chaplaincy and the basic characteristics of these instruments. From this discussion, it may have become clear that the choice and implementation of PROMs are not to be taken lightly. In this section, I will use

the PROM cycle developed by the Dutch National Health Care Institute and the Dutch Federation of University Medical Centres (Verkerk et al., 2017) to provide some guidelines on how to go about this (see Figure 1). I will introduce the purpose of each step and highlight some important choices. More information (in English) can be found at the COSMIN initiative (Consensus-based Standards for the selection of health Measurement Instruments; COSMIN.nl).

During *Step 1* it needs to be decided for which of the three discussed purposes the PROM is to be used, who will be filling it out, and when and where this will be done. Although a PROM can be used for more than one purpose, each goal and context places different demands on the PROs to be included, the measurement qualities of the PROM and its ease of use. On the other hand, patients and care providers should not be overburdened by PROMs. Thus, this stage of the PROM cycle requires careful consideration.

The selection of PROs during *Step 2* should be a collaborative and iterative process between researchers, healthcare chaplains, patients, and – depending on the purpose – collaborative partners such as other care professions or funding bodies. That way, the most relevant PROs are selected. PROs are relevant when they match the purpose of the PROM and when they are affected by chaplaincy care. Existing research can be helpful when making this choice. For example, the LISA study discussed above shows that for healthcare chaplaincy, the levels of insight into one’s values and one’s life might be more appropriate PROs than other aspects of physical, emotional or spiritual well-being. Based on the review of 104 spiritual care assessments in the electronic medical records of patients at The Ottawa Hospital, Stang (2017) suggests that chaplain-

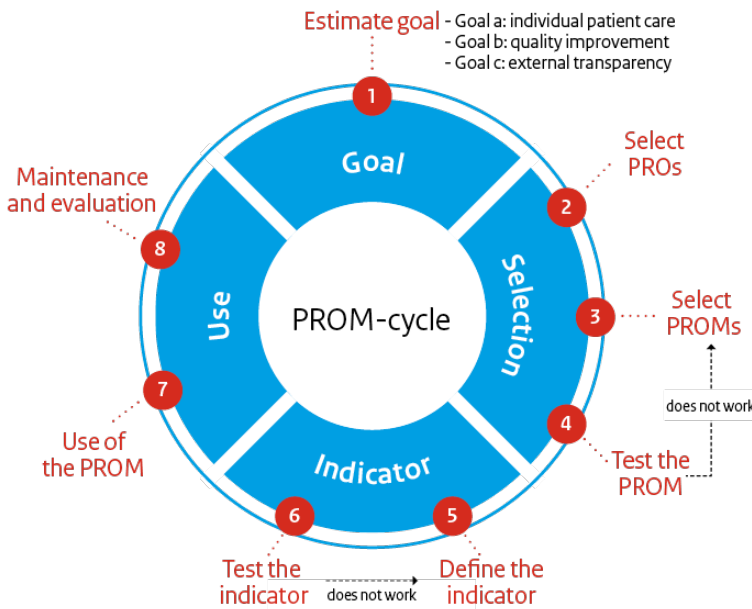


Figure 1. PROM cycle. Reprinted with permission from the Dutch National Health Care Institute (permission obtained on 22 February 2019).

cy is relevant when they match the purpose of the PROM and when they are affected by chaplaincy care. Existing research can be helpful when making this choice. For example, the LISA study discussed above shows that for healthcare chaplaincy, the levels of insight into one’s values and one’s life might be more appropriate PROs than other aspects of physical, emotional or spiritual well-being. Based on the review of 104 spiritual care assessments in the electronic medical records of patients at The Ottawa Hospital, Stang (2017) suggests that chaplain-

cy care affects patients' ability to express emotions; their levels of anxiety, peace, positivity, vigour, hope, spiritual coping, or comfort; and the quality of their relationships. The study by Flannelly et al. (2007) discussed above also stresses the importance of anxiety reduction and tapping into inner strengths and resources as outcomes of chaplaincy. Especially relevant is the question whether the PROM should assess chaplaincy-specific outcomes or outcomes that healthcare chaplains might have in common with other care professions.

After deciding on the PROs to be assessed, during *Step 3* a PROM is selected or constructed if it is not yet available. The first consideration here is which PROMs are already in use in the organisation so as not to overburden the users. It is advisable to use an existing PROM, because often the quality of these instruments is known, and comparative research or benchmarking are facilitated. However, the desired characteristics of the PROM need to be considered before choosing one: Should it be generic or disease-specific, how should it be administered (paper-and-pencil, electronically, by telephone, etc.), what should its psychometric properties be, and what should be the level of ease-of-use? Existing PROMs for each PRO can be found through systematic literature research or in databases such as PROMIS (healthmeasures.net), ePROVIDE (eprovide.mapi-trust.org/) or the Rehabilitation Measures Database (sralab.org/rehabilitation-measures).

Regarding the psychometric properties, several questions are important. First, the extent to which the content resembles the PROs to be measured (face validity). Second, what the validity of the questionnaire should be. A questionnaire has high validity when it measures what it is supposed to measure. Questions to be answered here are: Does it contain all the relevant aspects for the PROs, the target population and the purpose (content validity); how does this questionnaire relate to other questionnaires that are supposed to measure the same thing? I.e.: Does it really measure the supposed construct (construct validity); can the different PROs in the questionnaire be clearly distinguished from each other in the calculation of the scores. I.e.:

Does the questionnaire contain clearly distinguishable subscales (structural validity and internal consistency); how sensitive is it to change (responsivity). This is particularly important for repeated assessment as in ROM; and, if the target group is very diverse, is it applicable to groups with different (cultural) backgrounds (cross-cultural validity)? Third, how reliable the assessment should be. The reliability of questionnaire is high when the answers to the questions are not influenced by external factors. This is partly related to the ease of use. The PROM should be legible, easily accessible, not too costly, easy to fill out (Think back to the desired way of completing the questionnaire), easy to process, easy to interpret (when should a score be deemed high or low, what is a meaningful amount of change), and acceptable to patients and care professionals.

A selected PROM is tested in the intended practice during *Step 4*. It is determined whether the instrument is still valid, reliable and easy to use in the target group. In addition, the suitability for the intended purpose is tested. Should it not meet the criteria, a different PROM can be selected, the PROM can be adjusted, or a new PROM can be designed.

When PROMs are used for ROM, quality improvement or external transparency, it might be necessary to define an indicator (*Step 5*). In ROM a reference score is needed that indicates the difference between "ill" and "healthy", and between "meaningful change" (either good or bad) and "no or hardly any change". For purposes of quality improvement or external transparency, it might also be necessary to determine a score that indicated "good" versus "bad" performance. Such scores are called norm scores or cut-off scores. Indicators reflect the extent to which the patient, professional, department or organisation deviates from this norm or cut-off and is often expressed in a percentage. The choice of indicator has substantial consequences for the interpretation of the PROM, so it is important to involve all relevant parties and evidence in the decision-making process and to think very carefully about which PROM will be used, when and among whom, to ensure comparability of the criterion.

To ensure that the indicator is sufficiently comparable and discriminating it is tested in a small setting during *Step 6*. In other words, it is determined whether the indicator helps to detect actual differences between patients, professionals, departments or organisations. Should the indicator be insufficient, it can either be re-defined (step 5) or the PROM can be replaced, adjusted or (re-)constructed (step 3).

Finally, the PROM can be implemented in care practice for its intended objective (*Step 7*). Early in the process, practical concerns have been considered that reduce the risk of rejection of the PROM by its users, such as its understandability and ease of use. In addition, step 4 provided insight into various possible barriers to implementation and their solutions, to which the PROM may have been adjusted. Nevertheless, various arrangements might still have to be made to facilitate the implementation of the PROM, such as education of care professionals, adjustments in the care process, adjustment in patient registration forms, or encouragement by a leading figure. Two factors seem paramount to facilitate implementation of PROMs: To disrupt the usual care processes as little as possible and to reduce feelings of insecurity that professionals might experience about its use (Lambert & Harmon, 2018). Potentially, the feelings of insecurity do not only stem from a sense of unfamiliarity in using PROMs, but also from a sense of being judged. After all, the overarching purpose of using PROMs is to determine whether care professionals are “doing their jobs”. Clear and truthful explanations about the purposes and use of PROMs by management, an adjustment period before receiving feedback on performance with the PROM, supportive feedback, and early involvement of the users in the PROM cycle are important ways to manage such feelings of insecurity.

For fruitful adoption, the use of PROMs in the care process and the quality of the PROM need to be maintained and evaluated on a regular basis (*Step 8*). Evaluation should concern the relevance of the PROs, the appropriateness of the PROM, the level of use in the care process, and - if applicable - the quality of the indicator. Especially when the PROM is used for quality

improvement or external transparency, the scores can become so high that the PROM can no longer distinguish between good and bad practice (because all practice is good). If the objective of the PROM is not achieved or it is no longer relevant, various steps of the PROM cycle can be repeated or the use of the PROM can be discontinued.

Conclusion

PROMs are potentially useful instruments for outcome research in healthcare chaplaincy. The information can be applied to improve the quality of healthcare chaplaincy service and to communicate about healthcare chaplaincy with patients, (mental) healthcare providers, and funding bodies. However, implementation of PROMs in healthcare chaplaincy requires careful consideration of what can and should be measured, how it should be measured, among and by whom, when, and why. To be of most benefit, the content and use of the PROMs should match healthcare chaplaincy practice, which is diverse, multidimensional, sometimes unarticulated, and often unpredictable. The choice for using PROMs and the choice of PROs assessed reflect the vision on the profession and its responsibility. In this paper, I have provided some guidelines for the evaluation of these questions.

References

- Bos, N., Zuidgeest, M., Kessel, P. van & Boer, D. de (2015). *Ontwikkelen van patiëntvervalsings-vragenlijsten om kwaliteit van zorg te meten* [Developing a patient-reported experience measure to assess quality of care]. Utrecht: NIVEL. Retrieved from <https://www.zorginzicht.nl/ontwikkeltools/ontwikkelen/handreiking-ontwikkelen-prems>.
- Camp, R.C. (1989). *Benchmarking: the search for industry best practices that lead to superior performance*. Milwaukee, Wisconsin: Quality press for the American society for quality control.
- Damen, A., Delaney, A. & Fitchett, G. (2018). Research Priorities for Healthcare Chaplaincy: Views of U.S. Chaplains. *Journal of Health Care Chaplaincy*, 24(2), 57–66. <https://doi.org/10.1080/08854726.2017.1399597>.
- Damen, A., Schuhmann, C., Lensvelt-Mulders, G. & Leget, C. (2019). Research Priorities for Health Care Chaplaincy in The Netherlands: A Delphi Study Among Dutch Chaplains. *Journal of Health Care Chaplaincy* [Online First]. <https://doi.org/10.1080/08854726.2018.1473833>.
- Damen, A., Schuhmann, C.M., Leget, C. & Fitchett, G. (2019). Can Outcome Research Respect the Integrity of Chaplaincy? A Review of Outcome Studies. *Journal of Health Care Chaplaincy* [Online First]. <https://doi.org/10.1080/08854726.2019.1599258>

- Fitchett, G. (2011). Making our case(s). *Journal of Health Care Chaplaincy*, 17 (1–2), 3–18. <https://doi.org/10.1080/08854726.2011.559829>.
- Fitchett, G. (2017). Recent Progress in Chaplaincy-Related Research. *Journal of Pastoral Care & Counseling: Advancing Theory and Professional Practice through Scholarly and Reflective Publications*, 71 (3), 163–175. <https://doi.org/10.1177/1542305017724811>
- Flannelly, K.J., Oettinger, M., Galek, K., Braun-Storck, A. & Kreger, R. (2007). The correlates of chaplains' effectiveness in meeting the spiritual/religious and emotional needs of patients. *The Journal of Pastoral Care & Counseling* : JPCC, 63(1–2), 9–15. <https://doi.org/10.1017/CBO9781107415324.004>.
- Handzo, G.F., Cobb, M., Holmes, C., Kelly, E. & Sinclair, S. (2014). Outcomes for Professional Health Care Chaplaincy: An International Call to Action. *Journal of Health Care Chaplaincy*, 20 (2), 43–53. <https://doi.org/10.1080/08854726.2014.902713>
- Hjermstad, M.J., Fayers, P.M., Haugen, D.F., Caraceni, A., Hanks, G.W., Loge, J.H., Kaasa, S. (2011). Studies comparing numerical rating scales, verbal rating scales, and visual analogue scales for assessment of pain intensity in adults: A systematic literature review. *Journal of Pain and Symptom Management*, 41 (6), 1073–1093. <https://doi.org/10.1016/j.jpainsymman.2010.08.016>.
- Kruizinga, R., Scherer-Rath, M., Schilderman, J.B.A.M., Sprangers, M.A.G. & Van Laarhoven, H.W.M. (2013). The life in sight application study (LISA): Design of a randomised controlled trial to assess the role of an assisted structured reflection on life events and ultimate life goals to improve quality of life of cancer patients. *BMC Cancer*, 13, 1–9. <https://doi.org/10.1186/1471-2407-13-360>.
- Kruizinga, R., Scherer-Rath, M., Schilderman, J.B., Hartog, I.D., Van Der Loos, J.P., Kotzé, H.P., Van Laarhoven, H.W. (2019). An assisted structured reflection on life events and life goals in advanced cancer patients: Outcomes of a randomised controlled trial (Life InSight Application (LISA) study). *Palliative Medicine*, 33(2), 221–231. <https://doi.org/10.1177/0269216318816005>.
- Lambert, M.J. & Harmon, K.L. (2018). The merits of implementing routine outcome monitoring in clinical practice. *Clinical Psychology: Science and Practice*, 25 (4), 1–12. <https://doi.org/10.1111/cpsp.12268>.
- NIVEL, IQ Healthcare, VSOP (Vereniging Samenwerkende Ouder- en Patiëntenorganisaties) & Patiëntenfederatie Nederland. (2018). *PROM-wijzer 3. Hoe en wanneer werken PROMs?* [PROM-pointer 3. How and when do PROMs work?]. Retrieved August 1, 2019, from <https://www.zorginzicht.nl/ontwikkeltools/prom-toolbox/prom-wijzer-3.-hoe-en-wanneer-werken-proms>.
- Nolan, S. (2013). Re-evaluating Chaplaincy: To Be, or Not... *Health and Social Care Chaplaincy*, 1(1), 49–60. <https://doi.org/10.1558/hsc.v1i1.49>.
- Nolan, S. (2015). Healthcare Chaplains Responding to Change: Embracing Outcomes or Reaffirming Relationships? *Health and Social Care Chaplaincy*, 3 (2), 93–109. <https://doi.org/10.1558/hsc.v3i2.27068>.
- Pesut, B., Sinclair, S., Fitchett, G., Greig, M. & Koss, S.E. (2016). Health Care Chaplaincy: A Scoping Review of the Evidence 2009–2014. *Journal of Health Care Chaplaincy*, 22 (2), 67–84. <https://doi.org/10.1080/08854726.2015.1133185>.
- Selman, L., Young, T., Vermandere, M., Stirling, I. & Leget, C. (2014). Research priorities in spiritual care: An international survey of palliative care researchers and clinicians. *Journal of Pain and Symptom Management*, 48 (4). <https://doi.org/10.1016/j.jpainsymman.2013.10.020>.
- Sharma, V., Marin, D.B., Sosunov, E., Ozbay, F., Goldstein, R. & Handzo, G.F. (2016). The Differential Effects of Chaplain Interventions on Patient Satisfaction. *Journal of Health Care Chaplaincy*, 22 (3), 85–101. <https://doi.org/10.1080/08854726.2015.1133203>.
- Sinclair, S., Pereira, J. & Raffin, S. (2006). A thematic review of the spirituality literature within palliative care. *Journal of Palliative Medicine*, 9 (2), 464–479. <https://doi.org/10.1089/jpm.2006.9.464>.
- Snowden, A., Fitchett, G., Grosseohme, D.H., Handzo, G., Kelly, E., King, S.D.W., Flannelly, K.J. (2017). International Study of Chaplains' Attitudes About Research. *Journal of Health Care Chaplaincy*, 23 (1), 34–43. <https://doi.org/10.1080/08854726.2016.1250556>.
- Snowden, A. & Telfer, I. (2017). Patient Reported Outcome Measure of Spiritual Care as Delivered by Chaplains. *Journal of Health Care Chaplaincy*, 23 (4), 131–155. <https://doi.org/10.1080/08854726.2017.1279935>.
- Stang, V. B. (2017). An e-Chart Review of Chaplains' Interventions and Outcomes: A Quality Improvement and Documentation Practice Enhancement Project. *Journal of Pastoral Care & Counseling*, 71 (3), 183–191. <https://doi.org/10.1177/1542305017703127>.
- Terwee, C.B., Wees, P. van der & Beurskens, S. (2015). *Handreiking voor de selectie van PROs en PROMs* [Suggestions for the selection of PROs and PROMs]. Leiden: Nederlandse Federatie van UMC's.
- VandeCreek, L. (2004). How satisfied are patients with the ministry of chaplains? *The Journal of Pastoral Care & Counseling*, 58 (4), 335–342. <https://doi.org/10.1177/154230500405800406>.
- VandeCreek, L. (2001/2014, January 2). *The Discipline for Pastoral Care Giving*. New York: Routledge. <https://doi.org/10.4324/9781315809205>.
- Verkerk, E., Verbiest, M., Dulmen, S. van, Wees, P. van der, Terwee, C., Beurskens, S., Zuidgeest, M. (2017). *De PROM-toolbox: Tools voor de selectie en toepassing van PROMs in de gezondheidszorg* [The PROM-toolbox: Tools for the selection and application of PROMs in healthcare]. Diemen: Zorginstituut Nederland.

Notes

- 1 This paper will also appear in Dutch in slightly adjusted form: Visser, A. (2019). Patiënt-gerapporteerde uitkomstmaten (PROMs): Wat, waarom en hoe? *Tijdschrift voor Geestelijke Verzorging*.
- 2 Cf. the other contributions in this volume.